SUMMARY REPORT

OF

Community Forums on Assistive Technology

Sponsored by:

Tennessee Technology Access Project
Citizens Plaza, 11th Floor
400 Deaderick Street
Nashville, Tennessee 37248
Voice: 615-532-3122; TTY: 615-741-4566

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Prepared by:

Cecilia L. Mynatt
Center for Nonprofit Management
44 Vantage Way, Suite 230
Nashville, TN 37228
Telephone: (615) 259-0100 Fax: 259-0400

Community Forums on Assistive Technology
Summary Report of Five Sessions
(May 16, 2003)

EXECUTIVE SUMMARY

Tennessee Technology Access Project (TTAP) contracted with the Center for Nonprofit Management (CNM) in Nashville, TN to design, facilitate and document a total of five (5) forums that were held in Memphis, Jackson, Nashville, Chattanooga, and Knoxville from February – April 2003. The purpose of these meetings was to gather input from consumers, family members and community representatives about needs and issues related to Assistive Technology (AT). The facilitator asked similar questions in each group to guide discussion related to AT awareness, personal experiences, and ways to improve access to AT information and resources. TTAP will use the data in its planning process to help shape strategies that can be implemented at a statewide level to impact awareness of and access to AT resources.

Each group was hosted by the local Technology Access Center and was held for no more than two (2) hours depending on number of participants (range of 8 – 26 people per group). While unique topics were identified in each community, there were broad issues that emerged in every discussion. The key ideas discussed included:
- AT can include everything from simple self-made devices to sophisticated computer equipment.
- The primary value of AT is to enhance personal independence and quality of life in all arenas (social, educational, social).
- While there are many more AT options and resources available, the general level of awareness about AT is still very limited.
- Most people don't know about AT resources when they or a loved one might need to find resources.
- Many professionals who could be valuable sources of information about AT in different settings (especially schools, healthcare, rehabilitative) are limited in awareness about AT options.
- Barriers to obtaining AT include attitudes, limited funding, lack of access to provider, lack of expertise or training, limited evaluation, restrictions on use of AT, and long wait times.
- The most frequently mentioned ideas to increase access to AT resources were aimed at increasing awareness of AT within the general public and with target audiences (parents, healthcare personnel, educators, employers, students, and rehabilitation professionals).
- More funding is needed to increase access to resources.
- Personal and community advocacy are important strategies to increase the number of people who obtain appropriate AT resources on a timely basis.

The participants in every group expressed appreciation to TTAP for holding these forums and many people said they were interested in receiving the notes from the meetings.

INTRODUCTION

Tennessee Technology Access Project (TTAP) has historically relied on a Statewide Advisory Council (SAC) to provide consumer input and guidance as the organization has carried out its mission over the past ten years. In recent years, however, budget restrictions and constraints on Council member time have lead to a decrease in member participation. As a result, TTAP has developed a plan for securing input from consumers and other stakeholders throughout Tennessee. A key strategy for gathering this input is to hold facilitated forums in five locations convenient to each region of the State. The perceptions and ideas gathered in these forums will be used to assist TTAP in development of its strategic plan to address Assistive Technology (AT) needs of consumers and their families.

TTAP contracted with the Center for Nonprofit Management (CNM) in Nashville, TN to provide a consultant to design, facilitate and document a total of five (5) forums that were held throughout Tennessee in Memphis, Jackson, Nashville, Chattanooga, and Knoxville. The TTAP executive director and the consultant met with directors of the five Technology Access Centers (TAC) in these locations to clarify the purpose of the forums and to reach agreement on who would be invited, format of the group and roles of the Centers in coordinating the sessions. Each TAC director agreed to host and coordinate a session at his or her location. The hosting duties included identifying and inviting participants, providing transportation and telecommunication support as needed, providing refreshments and participating in the sessions. Without exception, the staff of each TAC location was generous with their time and efforts in support of these sessions and their role was critical to the project.

Participants
TTAP and TAC representatives agreed that participants would be invited from a broad list of individuals that might be identified through cooperation with local disability organizations and other key parties in each community. They also agreed to invite individuals to aim for an ideal mix of participants that would include approximately 75% consumer and family members and 25% other community representatives for a total of 12 – 16 individuals per group. Since these groups were informal in nature, the actual group mix at each site was based on who had the time and interest to attend and no efforts were made to restrict participants based on their identification as a consumer or other community representative. A total of 72 individuals signed in as participants in the for the five (5) sessions with attendance at each Center as follows:

Location:	Date:	Number of Participants
Nashville	2/27/03	15
Chattanooga	3/7/03	26
Jackson	3/11/03	9
Knoxville	4/15/03	8
Memphis	4/24/03	14

A list of all participants who signed in included as an attachment to this report.

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Group Format
Each session was scheduled for a 2-hour period to allow for arrival and wrap-up while the actual facilitated discussion was approximately 1 and ½ hour in length. The facilitator opened each session with introductions followed by introductory comments from the TTAP executive director. He welcomed participants, provided a brief overview of TTAP and the purpose of the session, and noted that input from consumers, family members and community representatives would be used to help TTAP update its strategic plan to ensure that Tennesseans with disabilities have the information, services and devices they need to make choices about where and how they spend their time as independently as possible. Following this introductory period, the facilitator described her role in guiding the discussion and asked permission to record the session for recall in preparing a summary report. She stated that none of the remarks from the group would be attributed to individual participants. The facilitator also noted that she would ask specific questions and would provide an opportunity at the end of the session for participants to offer other comments. She also noted that copies of the report would be made available to participants who wished to receive it.

Areas of Inquiry
The TTAP executive director and TAC directors worked with the consultant to identify the focus of questions that would be used to guide group discussion. Sample questions, developed to explore different aspects of AT in each community, were designed to guide responses so overall discussion themes could be discerned for the general topics. The areas of inquiry and sample questions designed to stimulate participant comments are listed below:

Level of Awareness about Technology-related Resources and Assistance:
- *When you hear the phrase "Assistive Technology (AT)," what is your top-of-mind definition?*
- *How would you describe the level or general awareness in your community about the availability of AT?*
- *To what extent is information about AT available in your community?*
- *To what extent are AT resources and assistance available in your community?*
- *Do you think community awareness of AT resources have changed in the past several years? If so, how?*

Past and Current Experiences with Assistive Technology*:*
- *Are you personally aware of examples where individuals with a disability have benefited by AT? Please describe.*
- *If you have personally used an AT resource, please describe your experience with the service.*
- *What are the barriers to obtaining information about AT?*
- *What are the barriers to obtaining AT resources? (Are there distinctions between public and private?)*

Access to Assistive Technology Information and Resources:
- *What could be done in this community to improve access to AT information?*
- *What could be done to improve access to AT resources? (What is included in reference to "resources?")*
- *What resources are needed, but not currently available, to provide access to AT information and resources?*
- *How supportive are local schools in providing access to AT?*
- *How supportive are local employers?*
- *Are there ways that consumers could be better supported to advocate for themselves?*
- *If you were a consultant who has been asked to give advice on what this community can do to increase opportunities to increase access to AT, what advice would you offer?*
- *If you were asked to give advice on how to improve the quality of AT, what would you recommend?*
- *Any other recommendations about how to improve the experience for the consumer?*

Wrap-up Discussion:
- *Who should we have invited to this meeting that is not represented?*
- *Would you like to receive follow-up information on the input gathered at the five community forums?*
- *What questions or comments do you have that we haven't covered?*

SUMMARY OF PARTICIPANT COMMENTS

This summary is organized according to topics that were explored within the Areas of Inquiry noted above. While each forum followed this general structure, specific questions varied with the issues and topics raised by participants.   Not all of the questions were addressed in each session. The facilitator sought to encourage broad participation rather than adhere strictly to time limits or an effort to obtain responses to each question. When the input of all five groups is considered, all of the identified topics were explored and discussed. This summary is intended to describe the themes and ideas that emerged from the five sessions as a whole. The topics addressed in this summary have been identified in an effort to provide the reader with a logical outline of issues discussed in the groups. Some participant remarks are included to illustrate content or tone related to topical areas.

Level of Awareness about Technology-related Resources and Assistance

In each group, the facilitator asked the same opening question and requested that each participant respond in round robin fashion. The opening question was: **When you hear the phrase "assistive technology," what is your top-of-mind definition?** The responses to this first question represented the wide **range in perspectives of the individuals** in each group. Many participants were consumers, parents, or loved ones who spoke from their personal experience. Some people responded from the perspective of student, teacher, employee or employer, service provider, and/or

community advocate. Several individuals described their long-standing use or interest in AT while others noted they have only recently needed or learned about AT options and resources. One individual said he had "been involved with every phase of technology," but didn't know about AT until he recently needed assistance. Someone else stated "you become champion of a cause when you become part of a cause." Within the five groups, consumers and family members discussed AT specifically related to individual needs. Regardless of the individual point of view some themes were prominent in the responses.

Many people emphasized that **AT encompasses tools and devices from simple to complex**, self-made and inexpensive to sophisticated and costly. The list of items specifically mentioned at least once in any of the groups as an example of AT includes at least: computers and peripherals, a back scratcher, televisions and VCRs, JAWS, a typewriter, pencil grip, glasses and contact lenses, augmentative and alternative communication devices, cameras, door handle, adapted toys, wheelchairs, door bell, door holder, TTY, self-devised brochure folder, Liberator communication device, cane, output device, Universal Design, environmental controls, a scanner, Braille, bed lifts, shower chair, raised line paper, button hooks, and grippers ("like the one sold by the Oxy Clean guy"). Several participants described AT as tools, equipment or devices. Some participants noted that AT also includes services and other resources, including people. One person said that the best AT he had as a college student was a "blind guy who stayed across the hall from me who was a genius with computers." Someone else commented that AT "is more than a tool, it's a concept of how to help people function." Another person proposed that the single best word to use to describe AT is "solutions."

In discussing the purpose or value of AT, the most frequent references were made to **enhancing the quality of life and personal independence**. Many participants emphasized that AT helps an individual with daily activities and "daily chores." One person offered a simple statement that seemed to capture this sentiment when she said, "AT can be anything that lets a person do what they want to do." Someone else said that AT can help in doing anything "faster, easier and better." Several people spoke about the value of AT in specific settings including home, employment, education, and social, and many participants discussed the value of AT in helping individuals "assimilate into society." One person noted that AT provides "access to continued learning" and the ability to be "present when I can't be there physically." Another person speaking from personal experience said, "AT has opened new worlds." Others offered comments such as "AT helps people live life to the fullest" and its "anything that enhances the ability to live independently." Some people described AT in terms of helping to "overcome limitations" or "replace a skill or something lost." Many participants, however, noted that the value of AT is "not limited to people with disabilities." Several individuals described glasses and contact lenses as examples of AT and commented, "all of us will need more help as we get older." Another participant discussed the broad appeal of universal design and also noted that technologies such as voice dictation are widely promoted and used as a desirable computer feature. Someone else described AT as "compensatory rather than remedial" in meeting individual needs.

In discussing the general concept of AT, several participants described how **many more**

options and resources are available now than in the past. One person spoke frankly in saying "from a selfish perspective, there are opportunities now that would have helped me 20 years ago." Several people described the importance of AT in day to day functioning and one person said, "AT is not an option, it's a right." Participants in each group described the future development of AT resources in positive terms with phrases such as "ever evolving" and "getting better all the time." One comment in particular that may sum up the overall view of AT as a resource in the future was "This is a great century to live in because AT is only going to get better."

The second question asked of each group was "*How would you describe the level of general awareness in your community about the availability of AT?*" This question about general awareness prompted observations related to personal experience, perceptions about public awareness, and awareness levels within specific community settings. It is important to note that participants in many of the groups offered strong commendations about the role of the local Technology Access Center in increasing awareness of AT issues in many settings.

Many people **related the issue of awareness to their personal experience as a consumer, family member, provider, educator or advocate**. Several parents commented on the interactions of people with a child who uses augmentative communication devices. One person noted that "people are curious about my son" and another parent said "people have no idea how to communicate with my son so he is limited to academic and medical settings." Many consumers and family members discussed their challenges in finding AT resources, especially as an adult with new AT needs or for a child with changing needs. Several participants discussed the importance of self-advocacy and the value in educating others "one person at a time" about AT. Some people discussed the challenge of locating the right resources at affordable costs. One participant said, "There is a lack of knowledge among individuals who need AT… we may not know what we need or where to find it." She described the challenge of finding a contractor who could incorporate a roll-in shower in house building plans.

Most people described the **public level of awareness about AT as low**. One person's response to the question about the level of awareness in his community was "nonexistent." Someone observed, "It takes 3 generations for changes to occur in society" and noted "computers have been common for only one generation." Another person said that most people do not see people using AT in public very often. Several participants in different groups commented on what one individual called "the fear factor," or uncertainty on the part of many people to approach or interact with someone who is using AT especially for communication. One parent observed that "people are in such a hurry, they don't want to take the time to communicate with my son."

In discussions about levels of community awareness of AT resources and issues, many participants identified **barriers within specific settings including healthcare, schools, and employers**. Several people spoke about their personal experience of **getting a diagnosis or treatment** from a physician who did not advise or suggest AT resources. One person described his experience in seeing several physicians for a progressive vision impairment and emphasized that "no doctor ever told me about AT."

A parent of a four-year old with special needs commented, "It's taken me 4 years to find out about (the TAC)" and asked, "Why didn't the pediatricians or hospital tell us?" Someone else commented, "The different doctors I've been to told me what I can't do, but not what I can do or could be able to do." A parent offered her observation that perhaps physicians "don't really understand all the devices that are available." Another participant with a progressive disorder said the doctors described what would happen at each stage, but that no doctor ever said, " when this happens, there is a device that can help you." Someone may have captured the sentiment of several participants when he commented that the medical community "only looks at you as a medical case."

Another prevalent theme in the discussions about awareness was the lack of information or support provided within the **public school system**. Parents repeatedly reported their perception that educators are not knowledgeable about AT devices and/or not supportive in supporting their use in the classroom. One mother expressed frustration that personnel within the school "didn't volunteer any information about output devices." She learned of a device that would help her son and then "had to wait months to get it." A common concern identified was the scarcity of AT resource staff within the school system. Whether from an insider's view or that of the parent, there is agreement that the lack of staff dedicated to AT resources throughout a school system impacts the availability and quality of support for AT. In one group discussion, several participants described how computers were available in the classroom, "but they don't know how to use them." In that community, the participants found it was important to determine what type of training and support teachers needed and then to provide it even when if it meant "starting with the basics." Several people said that more funding is needed to improve awareness and support for AT in the school system.

One parent said, "Even within special education, they didn't tell me anything that would help," and that she had to educate the educators about how to support and interact with her child. An educator in one group expressed concern that teachers may have the attitude of "looking for a piece of equipment to fix the child." She also commented "we are trying to fix the classroom, not the child." Another participant in the same group emphasized the need for a new paradigm that is "an independence model, not a remedial model." At least 2 parents of children in upper grade levels described a more positive experience with teachers who were enthusiastic in supporting student success with AT in the classroom. "One teacher last semester told us she would do everything possible to help with the technology," said one parent. Another parent stated he has seen "improvement in past several years" with support and cooperation from people in the school system. Parents in two groups expressed frustration that the school did provide an AT resource, but "restricts the use of the device" to certain settings.

Several participants discussed their experience related to **AT awareness in seeking employment or working at a current job**. Most people who discussed employer awareness of AT described a level of resistance because "they think it will cost a lot of money." Someone stated, "There is a tremendous lack of awareness in this region, especially among corporate America because they are worried about the cost." Someone described his perception during the job hunting process that potential employers where "trying to figure out what to Put of the EOE report about why they would not hire me." In some groups, individuals discussed their own experience of

using AT in the workplace. One person mentioned that she told others in the work setting about her use of AT and this prompted interest and questions. Another individual who described a positive workplace experience share his motto about the workplace: "if you are going to work with a person with disabilities, you must have patience and adjust to them just as they will have to adjust to you."

The overarching message in nearly every group's discussion about awareness of AT resources and issues can be summed up by one person's comment on the topic: "Many more people would benefit if they knew that AT exists." And in spite of the lack of awareness or misunderstanding about AT resources, a significant number of participants expressed their view that some progress has been made on this front. Many people, as noted later, were enthusiastic in identifying strategies that could increase awareness of specific groups and within the general community.

Past and Current Experiences with Assistive Technology

The facilitator asked participants to share *personal examples or observations about individuals seeking AT information or resources*.   Many people spoke about their own experience, as a consumer, parent or other loved one. Perhaps the most consistent message was heard from **parents** who presented one example after another of the "never ending quest to get what you need" as one person described it. "You have to fight every step of the way to get what your child needs," commented another parent. At least one parent discussed the impact of the class action lawsuit in making AT resources readily available to her child. In all other cases, parents expressed frustration with the perception that they must continuously "push schools" to obtain AT information or resources. One parent talked about how she finally obtained speech therapy at the recommended frequency for her child. Other parents gave examples of school personnel responding to requests with statements such as "if your child gets this, then everyone will want it" or "we will have to cut back on lunches to provide this to your child." Many parents discussed the stress and "burnout" that is experienced as they tried to get needed AT services and support." In one group, a participant described her increased level of stress "when I became a single parent and just couldn't keep it up." Several people acknowledged the "unfunded mandate" within the school system to provide services, but many participants identified attitudinal barriers as being at least as significant as limited financial and human resources.

The opening question for each group about the definition of AT prompted many participants to describe the **benefits he or she experiences as a consumer of AT**. As noted earlier, many people described the benefits of AT in terms of quality of life, independence, and the ability to "do what other people take for granted." Still other people described AT as helping them to "live life to the fullest" and more specifically to improve access to learning, working, participating in society, and "opening up whole new world of living."   Some people provided examples of employers who were supportive in adapting the work setting to individual needs and others discussed the specific AT devices that increased the ability to live independently.

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When asked about the experience of seeking AT resources or services as a consumer, participants in every group credited the local Technology Access Center with improving access to AT. The participants who discussed their experience in working with public sector services more frequently identified "red tape" and lengthy waiting periods as sources of frustration in obtaining AT. Participants in every group were also consistent in identifying **barriers to obtaining AT**, whether through public or private sources. Included in the list of identified barriers are:

- **Attitudinal barriers**: Many participants gave examples of meeting resistance to obtaining AT, particularly in the school or work setting, because of misconceptions about cost, impact in the setting, etc. One example was given of a student who finally obtained a computer in the classroom, but the teacher didn't use it during the year because it made a noise.

- **Limited financial support**: Many people mentioned lack of funds as a barrier to obtaining AT. Several participants discussed limitations on TennCare and other third party insurer benefits as a significant barrier. Others identified lack of funds to provide expertise and support in the school system as the "unfunded mandate." One example repeated within several groups was that of children who had outgrown a wheelchair but were not yet eligible for a new one.

- **Difficulty in locating or accessing the AT service provider**: Several people talked about not having information to locate providers when needed, and then having to travel a significant distance several times to apply for resources. Some participants mentioned lack of transportation as a specific barrier while others noted lack of childcare and/or other supports as a barrier to accessing services.

- **Lack of training or expert assistance**: Several participants emphasized the importance of having access to training and/or support in use of AT. One person described how a spouse obtained computer equipment but could not use it without training. Several people mentioned that limited funding was creating a lack of knowledgeable programmers, which had lead to people who were ready to go to work having to wait until a programmer could be recruited. In one group, there was significant discussion of the need (and examples of solutions) in providing training to special education and other teachers on the use of AT.

- **Limited or inadequate evaluation:** Many people emphasized the importance of having an adequate assessment of individual needs by a trained professional as a prerequisite to the effective use of AT. Several participants credited the local TAC with playing a key role in conducting or ensuring a good assessment of the individual's needs at different stages of his or her life and as applicable to more than one setting. One person also noted the critical importance of "having the right physician" in identifying and meeting AT needs.

- **Restrictions on use of AT in different settings:** Several parents mentioned that AT equipment provided in school was restricted to use there, which limits opportunities for learning and interactions in other settings. One parent noted the lack of opportunities for children who use AT devices to interact in social and informal settings.

- **Waiting time:** Many consumers and parents gave examples of having to wait for lengthy time periods before the appropriate AT resource could be identified or obtained. The issue of long waits was particularly mentioned with regards to public sector service providers.   Some people attributed the delay in obtaining

AT resources to "red tape."

Access to Assistive Technology Information and Resources

In each group, the facilitator asked questions to gather ideas on *how to increase access to AT information and resources.* These questions generated enthusiastic responses from participants who offered many suggestions and ideas to improve access to AT. Some ideas are geared for the general public while others are targeted for service providers who may have contact with consumers and family members, and other specific groups. Many people also suggested marketing and communications strategies to effectively increase overall awareness about AT.

A prevalent theme in the discussions about improving access to AT was an emphasis on the **need to increase general public awareness of AT resources**. As one person noted, the intent of many of the suggestions is to "make sure you have the information you need when you need it." Many consumers and family discussed their own experience of not having access to information on a timely basis, which meant they, or a loved one unnecessarily spent months or years without AT resources. Some people talked about the value of **different electronic and print media** to promote information about AT. Several people suggested that greater use of pubic service announcements as well as talk shows on radio and television. One person commented that features about AT on mainstream television shows such as Discovery and others would be effective ways to educate the public. One tongue in cheek suggestion was made to "use SPAM to promote AT awareness."

There were also suggestions about **posting information or brochures** in public locations including churches, community bulletin boards, and guidance counselor offices. Many people proposed that doctors have relevant information and product demonstrations available in their offices. One person provided the example of an optometrist having information relevant to AT resources for people with macular degeneration. Other participants suggested ways to "**get AT out there**" such as installing closed captioning televisions in nursing homes and libraries. Some people also proposed having **demonstrations of AT resources in public locations** and using the mobile unit (available through one TAC) for this purpose. These suggestions were aimed at increasing awareness of the local TAC and its services as well as AT resources. There was discussion about promoting and holding open houses and tours of the local TAC. In several groups, there were comments about the need for **a well-publicized central point of contact** so people in the community would readily have a phone number to call for more information, or a database to access that would provide resource information. Of note, there was recognition within several groups that the local TAC was already implementing some of these strategies.

Much of the discussion about improving access was related to ideas about **educating or influencing attitudes of professionals in different settings**. Many people shared personal experiences with **physicians and other medical professionals** who had not been helpful to consumers and family members in learning about AT resources at critical times. Some participants attributed the lack of support from the medical

community to "the medical model." Several people said in one way or another that doctors "see the disability and not the abilities." One parent commented, "We never heard what our daughter could do (from doctors), only what she couldn't do." The same parent pointed out that his daughter was now "doing everything they said she couldn't do." There was significant discussion about the need to impact the attitudes of medical professionals and their understanding of AT resources. People commented on the importance of providing more training to students in medical, nursing and other healthcare fields about AT and about the Independent Living vs. the medical model. One parent described her and her son's experience in doing presentations with an Occupational Therapy class as having impact on students.

In some groups, there was discussion about the value of **providing training for other professionals** who may be in contact with people who want and need AT resources. Several people noted that many caseworkers, social workers, counselors, and other service providers are not aware of AT resources. One person said, "They need more training and experience." Several participants commented that with high turnover in these positions, the need for training is continuous so new employees gain needed information. Suggestions were made to hold symposiums, bring them to TACs for training, and invited them to AT trade shows. The idea was also raised in more than one group to incorporate AT into university programs for all professionals in teaching and helping professions. Several people gave examples of teachers certified in special education who were unaware or very limited in their understanding of AT resources.

In each group, participants discussed the **need for more awareness and support within the school system** for AT resources. Many participants, including parents and professionals, emphasized the need to provide more training for teachers on what AT is and how it can help students in the classroom and other settings. Several people described teachers who had initially been resistant or fearful about AT and after having a positive experience with a student in their classroom became more receptive and knowledgeable. There were observations about the misunderstandings that many teachers and school personnel have about AT including concerns about cost, disruption or difficulty of use. One person from a school system emphasized the need to "make sure they know the full range of AT." Several people talked about the importance of "common sense" in considering the types of AT resources that can be helpful to a student, from simple adjustments of worktables to communication devices.

In one group, several service providers shared examples of how teachers had responded well to training. "It's important to understand and meet the teachers' needs, even if you have to start with the basics," said one person. Overall, many people expressed concern about the resistance and lack of innovation in the school system with regards to providing AT that meets the needs of the "whole child." One person observed, "The education system stifles innovation."   Many parents also expressed frustration that AT might be provided but limited to the school setting. Even when AT is used in the classroom, said one person, "they don't transfer its use beyond school so the student is limited in other environments."

There was discussion in several groups about the importance of **increasing awareness**

and understanding among employers about the benefits of AT in the workplace. Some people discussed the need to educate employers as a strategy to increase access to AT resources and application to the work setting. One person described the opportunity that is emerging for people with disabilities to be hired by employers who are increasingly interested in meeting diversity goals. The "3 Es'" of successful efforts to increase job opportunities for people with disabilities are "exposure, experience and expertise," according to this participant. He also pointed out that employers are looking for the "business case for hiring a particular person and would be willing to make accommodations." Several people described examples of employers who have hired people who use AT are more likely to understand the value of AT in the workplace. In one group, there was discussion about how schools could do more to support students in making the transition from the classroom to work setting by having more knowledge and understanding of AT applications in different settings. Someone emphasize the value of having a knowledgeable professional working with any individual in securing employment and AT resources appropriate to individual needs in the workplace.

At least one person in each group identified the **need for more funding** to increase access and availability of AT. Many participants observed that lack of funds is a significant barrier to obtaining needed AT resources. Several people suggested that greater flexibility on the part of public agencies in criteria for purchases of AT resources could be very helpful in making sure "the needs of the whole person are considered." Some participants discussed how restrictions on the use of AT to specific settings limits an individual in living a full and independent life. In consideration of ways to increase access to resources, several people suggested use of "exchange," loan closets, or websites where consumers can obtain specific used equipment and low or no cost. Someone also mentioned the availability of a low interest loan program that is available to people who may not be able to afford specific AT resources.

In discussions on different topics related to increasing access to AT information and resources, many people identified strategies aimed at removing attitudinal barriers. One person said, "Society marginalizes people with disability and until we change that it is more difficult to make other changes." Several participants noted that the more people who use AT are visible in the schools, workplaces, recreational and other settings, the more aware the general public is of the possibilities and benefits of AT.   Other people discussed the importance of self-advocacy in gaining access to AT resources. Someone commented, " You have to be a squeaky wheel to get what you need."

The facilitator asked participants in each group to comment on *how people can be better supported to be advocates for themselves or others*. Many people discussed the value of **having information on personal rights and specific resources** as important tools for self-advocacy. Some participants described the value of access to a database with information about resources as a good first step in advocacy. In one group, someone shared the recent availability of a national database of resources called the "Hub" on the Alliance for Technology Access website (www.ataccess.org). One participant underscored the need for consumers to have good information in order to have choice and to make informed decisions. Several people discussed the importance and effectiveness of support groups. The STEPS

program was mentioned most often and one parent said, "it was a major lifeline" in getting needed information. The TIPs and PEP programs were also mentioned. Someone in one group agreed on the value of these organizations, but commented that too many parents were unaware of the resource and estimated that "75% of parents don't know they exist." Several parents shared from their own experience the difficulty in "always having to push to maximize opportunities" even when supports are available. Someone suggested that "support groups for AT users" would be helpful. Other people commented on the value of support that is available through the Internet. One parent said she was able to get a sample IEP from someone online and it was very helpful in preparing for her first meeting.   Someone said, "have a computer and know how to use it – it's the great disability equalizer."

Other observations about how to support people as advocates included accolades for the Partners program. Several people said the program was effective and also noted that **more opportunities are needed to teach and learn advocacy skills**. One person pointed out that some people are "more likely to be advocates than others because of personality." Suggestions for ways to provide more training include seminars, workshops, mentors, and videos. Several people described low attendance at workshops and noted barriers of time and transportation. Other people suggested using "technology to reach people." There was also discussion about distributing packets of materials on specific needs and resources in convenient locations such as providing written materials to parents on support groups, rights, etc. at the IEP meeting. Some participants observed that service providers also need training on advocacy skills and should play a more active role in supporting personal advocacy efforts of consumers and family members.   Several people in different groups commented on how helpful the TAC had been as an advocate or supporter of personal advocacy. One person noted that TTAP funds at the TAC had provided support for effective outreach efforts.   Several people emphasized the importance of "speaking with one voice" within the disability community to advocate for changes. In some groups, one or more participants described advocacy as important in "the fight to secure basic civil rights." One person summed up his feelings on advocacy when he commented, "It takes all of use together."

<u>Wrap-up Discussion</u>

The facilitator closed each group by inviting participants to comment on something that he or she wanted to discuss that had not yet been mentioned or with any other closing remarks they wish to offer. Nearly all **participants in every group either added a new idea or observation or reiterated a point that had been previously discussed**. These comments are paraphrased below and organized by the general topic.

Closing Comments:

Need for Awareness/Education:
- Invite new counselors to the center (TAC) for tour.
- New professionals need time to "play" with AT resources, to get comfortable with it through hands-on experience.
- Use television to increase awareness of AT. Reach out and partner with other groups.
- Train volunteers to make presentations (to offset budgets cuts).
- Educate employers, medical professionals, therapists and others – get the word out!
- We are dealing with "fear and pride" – lack of real awareness about AT is the barrier.
- Bring employers and HR managers to a forum. Ask the Chamber to sponsor it.
- Make sure legislators know about the importance of funding for AT.
- "Insert" AT in the curriculum for special education teachers.
- Bring students to locations where people are using AT.
- In spite of all the problems, the situation in the schools is getting a little better.
- Inclusion in the schools will help over time.
- We need to start awareness efforts by educating the school system.
- We need to think outside the box about how to get AT vendors to showcase different products and services.
- Let people know that "AT can be anything."
- Insurance companies don't know about AT – they need to be more aware.
- The general public needs to be more aware of AT because when you do need it you won't know where or how to find it.
- Money is a problem but so is training. You can have the resource but without training it is useless.
- We need more people visible in the workplace. This will lead to more employment opportunities.
- There is a need for training and support for parents on what to do at each step of a child's development.
- It's about impossible to explain AT to people who don't use it. You have to show them.
- Take your children to public places so people will see what they can do.
- I'm amazed at the lack of awareness about AT. PR is important.
- Work with insurance companies to provide information and support to new quadriplegics so they will have access to resources.
- Maybe TTAP could do more PR to demonstrate what AT can do for people in all areas of life.
- Use an advertising company to get the word out.
- We need PR to show people with disabilities, using AT, in every day life.
- Get more PSAs.
- Start with schools to educate people about AT.
- We need to do a better job of awareness.
- We need to market AT to let people know what is available.

Attitudes:

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- "Why do you think people with disabilities are underestimated? It's attitude… when people take the time to know someone, to give us a chance, the attitude changes… It's up to us to change the attitudes."
- Some people (in the helping professions) are not motivated by caring for people with disabilities – it's just a job.
- Even people who work within the disability community put limits on what people can do. We all need more awareness and training.
- Even with the ADA, you still have to fight to get employment. The burden on the applicant is way beyond what it should be.
- Laws don't overcome attitudes. We have to change attitudes… "We know what we're up against."
- Get out success stories to change attitudes.
- "Personalize the message" about the value of AT.

Resource Issues:
- There should be one location where people can turn based on their functional need.
- We need to work with companies (like Wal-Mart) to make AT more affordable. Many items are widely used but cost more through special sources. Voice input equipment used to be $9,000 - $10,000 but is now less than $100 because everybody wants it.
- Network and support groups are important. When you are in a good network, you know who to call.
- We are providing AT equipment in local career centers and want to let the community know about that resource.
- There is a need for more lending programs for people who can't afford AT.
- The easier technology is for the user, the better it is as a tool. Not everyone is a "techie."

Frustrations, Observations, and Solutions:
- We are all frustrated – those providing services and those receiving services. It's not just our city or state either; it's across the country. Maybe more discussions like this one will help us find the answers.
- This is like the struggle for civil rights. We need to stick together and help each other. If we don't do it, who will?
- "We (people with a disability) can't do anything, but neither can other people. I can do a lot and I concentrate on what I *can* do."
- I want (what everyone else wants)… a job, a place to be with people my own age, and a spouse.
- It's good to know I'm not the only person who is frustrated – this kind of group is good.
- This is a great forum.
- Invite state representatives and medical personnel to these groups.
- Include adults with progressive disorders in the group.
- We have to be our own advocates and take the time to let other people know us.
- This type of meeting is good. Thanks for including me.
- This is a great advocacy group that could create a network to get things done.
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- I have a big concern that funding for PR and outreach will limit what we can do.

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There is a tremendous need across the state.
- I'm discouraged about the school system, but I'm encouraged by the scope of skills and experience in this room.

CONCLUSION

The focus group approach to collecting primary data is often useful for exploration of stakeholder perceptions, attitudes, and preferences. The input from these sessions cannot be considered as representative of an entire community since the number of people involved is limited and participants were not randomly selected. The participant comments, however, can provide insight about the beliefs and perceptions of people from these different communities.   When the comments from participants in the five groups are considered in total, there are certainly themes and issues that are shared by representatives from all five communities. In each of the groups, several participants commented on the value of coming together and expressed appreciation to TTAP for holding the sessions.